

What happens when we die?

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in the months leading up to her death, Julie Winnefred Bertrand, the world's oldest woman, had started to withdraw from the world around her.

The 115-year-old Montrealer had taken to sleeping for long stretches, sometimes 48 hours at a time, and often dozed through family visits.

Once social and involved in activities at her Ahuntsic nursing home, she rarely left the confines of her sixth-floor room at Residence Berthiaume du Tremblay anymore.

So on Jan. 13, when out of the blue she asked for a complete tour of her nursing home - something she had never before requested - the nurses were surprised.

She asked to visit the chapel where she had prayed, the bank and depanneur on the building's main floor, and the salon where until two years ago, she had her hair done unflinchingly once a week.

With the help of a nurse and a wheelchair she did it all, taking time to pause at the main doors of the home she first entered 32 years ago.

Then, it was over and she returned to her room.

Five days later, on Jan. 18, she died peacefully in her sleep at dawn.

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Death. It's the final page of life, but in a society where dying has been institutionalized, rarely is it ever discussed and, as a result, it remains shrouded in mystery.

However fleeting, Bertrand offered the rest of us a glimpse into what many of us will experience when we die.

"Near death awareness" is a term used by doctors, nurses and palliative care workers to describe a constellation of unusual behaviours observed at the end of life.

"We all know we are going to die ... one day," said Teresa Dellar, a Montreal social worker and director of the West Island Palliative Care Centre.



CREDIT: JOHN MAHONEY, THE GAZETTE

Nurse Maxine Lybert plays cards with patient Fawzia Bachat at the West Island Palliative Care Centre this week. Rose De Angelis, the centre's nursing director, says palliative care nurses are ideally positioned to collect intimate details that can help educate society about death.

"This is different."

A woman so sick she had been unable to eat for weeks suddenly declares: "This will be my last meal." She requests bacon and eggs and eats them happily. She dies the following day.

A man agitated by his wife's approaching birthday decides to celebrate the occasion early. He orders her favourite flowers. They arrive the day he dies.

A woman demands a nurse call her husband at 3:20 a.m. to make sure he is okay. Despite the hour, the nurse relents. She finds the husband is in need of emergency medical care. The woman dies within 48 hours.

After spending three months at the palliative care centre, a man estranged from his parents decides it is time to call them. He picks up the phone and dials their number. He dies a few days later.

Near death awareness, Dellar said, is the often unconscious recognition that death is just days or hours away. It can be accompanied by a burst of energy that allows the dying to

carry out last wishes, to right wrongs and say goodbyes. Families, though, can be left confused, uncertain what to make of it all.

The term "nearing death awareness" was coined in 1992 by two U.S. hospice nurses, Maggie Callanan and Patricia Kelley. They were among the first medical professionals to identify a phenomenon that is now recognized worldwide.

After following hundreds of terminally ill patients, Callanan and Kelley documented the phenomenon, which is characterized by premonitions, visions, dreams and unusual physical findings, in a book.

Final Gifts went on to become a sort of bible for hospice workers.

Now, closer to home, nurses at the West Island Palliative Care Centre in Kirkland are engaged in a similar qualitative exercise, collecting intimate details about the human experience leading up to death.

In the process of caring for the more than 650 patients that have received care at the centre since it opened in 2003, Dellar said the centre's 25 nurses have listened and learned and now want to share some of their observations.

An estimated 98 per cent of patients accurately predict when they will die - often within a day or two, but sometimes even to the exact hour.

In the final 72 hours, the dying person often experiences a burst of energy and mental clarity that they used to declare their love, say goodbyes and right past wrongs.

Patients report having dreams that revolve around travel - a sleigh filled with relatives, filling a car up with gas, a train leaving a station or a bus stopping and starting.

Many people report seeing a warm and welcoming light.

Visions of deceased loved ones are common. The dying reach for them, talk to them. "When will we be leaving?" one man asked. "Monday," was the accurate response.

"To keep these stories to ourselves would be unfair," said Rose De Angelis, the centre's nursing director. "We experience these things - if not daily - certainly weekly."

In some cases, Dellar said, there are plausible medical explanations.

Pain medications and other drugs used in palliative care can induce hallucinations. Dwindling supplies of oxygen to the brain could also be responsible for bringing on delirium. But, Dellar said, the inexplicable events are too numerous to be totally discounted as drug-induced.

De Angelis said nurses at the palliative care centre are ideally positioned to collect the kind of intimate details that can open a dialogue, help families respond appropriately and, more broadly, educate society about death.

"We ask patients about their dreams and their visions," she said. "That's not going to happen in a 40-bed surgical unit in a hospital."

"It's often very personal stuff."

Palliative care nurses are trained to know when to probe, when to listen and what to watch for.

Their observations are not necessarily the kind you find in "peer-reviewed journals," De Angelis conceded. But at the same time, she said, neither should they be fodder for the kind of hokey stories often seen published in supermarket tabloids.

"Just because it is unexplainable does not mean it is without value," she said.

De Angelis said her hope is that the end-of-life observations will educate doctors and nurses to provide better psychosocial and spiritual care to dying patients.

Some of the documentation, has already been presented at national palliative care conferences in Montreal last fall and in

Edmonton the year before.

Next month, De Angelis has been invited to Ottawa to share some of the stories at a national conference where Canadian nursing school administrators are reviewing curriculum.

De Angelis said the ability to read the behaviour of the dying is the kind of earthy knowledge we as a society once took for granted only 70 or 80 years ago, when people died at home, surrounded by family.

"It's time we reclaimed it," she said.

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Dawn Cruchet, a former CEGEP nursing instructor turned grief counsellor, is passionate about improving our knowledge of dying and near death awareness.

"In hospitals, (generally) we don't say death, die or dead. The word is expired as if we are yogurt or a parking meter."

The pervasive denial, she said, causes nurses, doctors and, consequently, family members to miss important clues about how much time someone might have left and what they might need for a peaceful death.

Leading bereavement groups, Cruchet said she sees how regret makes the healing process more difficult for surviving friends and loved ones. "Should haves, would haves and could haves" often dominate their minds.

"There's a huge need for education while people are dying to shape what is happening," she said.

Cruchet said her work at the Queen Elizabeth Health Complex Grief Centre as well as her volunteer work in palliative care wards has opened her eyes to the need for society to embrace death as a part of life.

"Listen to the dying," she said. "It may well be that only those people who die in palliative care are being helped in this way."

As part of a course she teaches at McGill University on demystifying death and dying, Cruchet said she asks students to explore their feelings about the taboo subject by writing papers on "my own best death," and "my own worst death."

Not unlike birthing, which has been transformed during the past few decades from a medical procedure to a natural event involving partners, she said, our experience of death needs to be redefined.

Just as we share "birth stories," she said, it is healthy to share stories about death.

Tom Hutchinson, a palliative care physician and the MUHC's director of whole person care agreed with Cruchet and took the birth analogy a step farther.

"When people begin to accept that death is not a fairy tale, that they are about to die, something new opens up.

"The analogy of birth is very helpful. We wouldn't think of trying to hold back a birth." Similarly, he said: "When we are in the final stages of life, months, weeks and days, we have to orient ourselves around that fact."

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As for Julie Winnefred Bertrand, no one will ever know for sure what the 115-year-old sensed in the days leading up to her death.

But Monique Jodoin, the nurse who escorted her around Residence Berthiaume du Tremblay one last time, has a pretty good idea.

"I was off-duty the day she died," Jodoin said this week. "They called me at home."

Immediately, she said, she recalled how "happy" and "satisfied" Bertrand had been in her wheelchair that January afternoon.

At the time, and until Bertrand's death, Jodoin said she had thought little of the tour.

"It took all of 30 minutes."

But in retrospect, she said, she couldn't be more grateful to have granted the woman she had known, cared for and respected for 31 years her final wish.

"I realized she must have known."

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